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men's, navy
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Our sincerest apologies to those whose names we may have inadvertently omitted from these acknowledgements.

With heartfelt gratitude . . . DDC Clinic would not exist without the generosity of our community of donors. The contributions and goodwill of our supporters truly makes a difference. Even as we receive much-needed funding for major projects, it is the contributions of individuals that enable us to provide services on a daily basis to our "family" of children. Please accept our sincerest gratitude and thanks.

On behalf of our Board of Directors, we would also like to extend our appreciation to these major donors from over the past few months: The Harry K. and Emma R. Fox Charitable Foundation, United Way donors in Lorain, Cuyahoga and Geauga Counties, the Kiwanis Clubs of Lander Circle and West Geauga, Burton Congregational Church, Children's Guild, Chagrin Valley Jr. Woman's Club, Loretta Mae Hausmann Holmes Foundation, Chagrin Valley Rotary Club, The Mindala Family Foundation, Nationwide Mutual Insurance Co., University Hospitals Health System, and the United Methodist Church of Chagrin Falls. Bless you all!

National Family Cohen Syndrome Meeting Held at DDC Clinic

Many of you have been following the story of DDC Clinic's discovery of 28 cases of Cohen syndrome within our community. Only about 100 cases are confirmed worldwide, with a cluster in Finland, where the gene was discovered.

The meeting allowed families the opportunity to share their experiences raising children with Cohen Syndrome as well as listen to several medical and educational professionals speak.

Today, we are pleased to report on the First-ever National Family Cohen Syndrome Meeting recently held at DDC Clinic. Sponsored in part by funding from United Way Services of Geauga County, the event drew members from 13 families from Ohio and as far away as Colorado, Massachusetts, and Alaska.

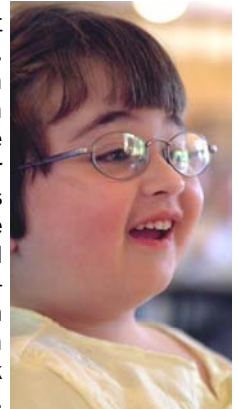
Dr. Wang spoke about primary healthcare issues for children with Cohen syndrome and common findings among them including neutropenia (low white blood cell count), anxiety, "super-hearing", and central obesity. He also spoke of the need for reduced dosing of medications in some children.

Also speaking was Elias

Traboulsi, M.D., from the Cleveland Clinic Foundation. Dr. Traboulsi is board certified in both ophthalmology and genetics. He spoke to families about the multiple vision problems that affect children with Cohen Syndrome along with current treatments and research implications that may benefit them in the future.

Gary Stotsky, a speech pathologist from York, Pennsylvania, addressed the issue of using alternative communication devices, such as picture boards and computers, to help patients better communicate.

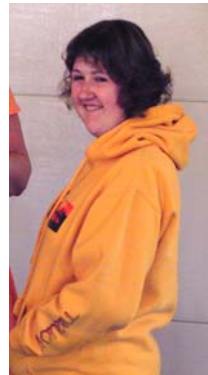
For the first time ever, children with Cohen syndrome and their families were able to see and talk face-to-face with children that look like them.



Families also enjoyed visiting and sharing ideas and strategies to help their children during a picnic that was held the following day.

Thank you Sonja Delano (Colorado) for writing this very special letter and sharing your story. Such extraordinary children and their families have truly captured our hearts!

Sonja writes: I very seldom stray far from home, so going to Ohio for the conference was a big thing for me. It was also one of the most wonderful experiences of my life. For the first time in almost 22 years . . . I was able to see other children like mine. That may sound silly, but for someone like me who diagnosed her own children after years and years of research and genetics appointments, who was constantly yearning and hoping for answers for 20+ years, who searched every time she was in public for faces like her daughters, it had a tremendous, positive impact . . .



There was little Jacque, who's mother Krista I

have been communicating with for months online, she looked like an identical twin for Debbie—the face, eyes, dark hair, and charming personality.

The commonality of all the children is just amazing . . . There was one mother there who has 3 daughters with Cohen syndrome. One of her daughters speaks, the other two don't. My Debbie speaks, Ashley has never spoken. There was a girl there who looks so much like Debbie, except she was thinner and much more developmentally appropriate. For me, that was looking at Debbie if she had "more", I don't know how else to explain it. It was not a sad moment, but a happy one. I got to see Debbie in a new light, if that makes any sense. The conference did something for me that no doctor could ever do; confirm in my mind that the girls' diagnosis was correct. There is great peace in that.

For me . . . it was the support of the other families that meant so much. In all of this I have been alone. Sure, there are support groups here, but it is not the same as hav-

ing the support of others who know EXACTLY what you are talking about. As I drove back to my hotel that night, I cried. At the hotel, I cried some more. This time it was with relief that while we are few, both us and our children, we know exactly how each other feels. We are not alone.

. . . Thank you for having this conference. . . I know that I will be bringing Debbie and Ashley to the next one so they can meet others like them. Maybe they won't know the difference, but I will.



The images shown on this page were taken at the Cohen syndrome meeting. We gratefully acknowledge photographer Danny Maple, www.relive.us, for sharing his time and talent in capturing the spirit of these beautiful children.

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